# NOTES FROM BED
## Learning from Chronic Illness

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I have lived with myalgic encephalomyelitis/chronic fatigue and immune dysfunction syndrome (ME/CFIDS) for over 20 years. At the beginning of a relapse, I cannot help noticing that I am more easily exhausted every day, but I still resist giving in to being sick. The increasing fatigue feels like a progressive humiliation of my will and ego as it forces me to cancel my plans and retreat to my bed. It also frightens me because, despite many experiences of emerging from relapses, I find it hard to believe that I will ever have any energy again. The chronic muscle pain over much of my body becomes more intrusive; it won't be ignored or overridden. I may be dizzy and/or nauseated. I slow down, far down, body and brain. Television becomes too stimulating, painfully so. Sometimes Gregorian chant is the only music I can tolerate. Because I can do them lying down and at my own pace, reading and writing, which are always important to me, become the central activities that give my daily life structure and meaning. In the depths of relapse, I am shamefully aware that I cannot begin to keep up with most human beings. Comparisons to other animals are even worse: they seem ridiculously energetic. Yet standing or sitting near a big tree can dispel a depressive mood, perhaps because the tree lives at a pace that comforts me.

Many illnesses, including ME/CFIDS, can diminish consciousness. Pain can interfere with imagination, perception, thinking, or feeling.

Brain states caused by illnesses or the drugs used to treat them can dull the mind or create such restlessness of mind that focus, even enough focus to read, may be impossible. Short-term memory can fail in illness, making it difficult to understand or speak a single sentence because one has forgotten how the sentence started before one can finish it. I have experienced all these forms of diminished consciousness at one time or another. Nevertheless, I have also found that it is possible to be both very ill and intensely alive. Consciousness can be more focused during illness, awareness heightened, even when the realm of action has shrunk to a room, a chair, a bed. Many people have commented on this, including William James (1902), Arthur W. Frank (1991, 1995), Kat Duff (1993), and Oliver Sacks (1995). Virginia Woolf ([1930] 2002) wrote this about it:

> Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a slight attack of influenza brings to view, what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals, what ancient and obdurate oaks are uprooted in us by the act of sickness ... it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature. Novels, one would have thought, would have been devoted to influenza; epic poems to typhoid; odes to pneumonia; lyrics to toothache. (pp. 3–4)

Last year, I spent most of six months sick in bed with gallstones and ME/CFIDS, waiting for a diagnosis, waiting for surgery, and recovering from surgery. Here is something I wrote then. It's a long way from an ode to ME/CFIDS (or gallstones), but I hope it conveys some of the intensity of that time:

> Lying in bed feeling very weak and often in pain, and depending on Bob (my partner) for most of my physical comforts and on him and my other friends for my emotional consolations, I realize the futility of professional ambition, compared to the importance of communicating and loving and writing for people who might want to read what I have to say. I also realize that dependency and even the shame I feel at having to ask for help, although they are painful, are also good insofar as they diminish my pride and my illusion of independence. They leave me feeling relieved at not having to maintain my persona of personal and professional competence, and connected to a deeper reality in myself and other people than I usually experience.

## IS IT ME OR AM I SICK?

Accepting (about 18 years ago) that the ME/CFIDS was probably not going away forced me to recognize that I was not a Normal Woman anymore. Now, I think the idea that I was ever a Normal Woman is ridiculous; I never belonged to that gender (if it exists). During my childhood and adolescence, I was often described by my elders (including some of my teachers) as too serious, too conscientious, too sensitive, and too smart for my own good. I also read too much, and the wrong things. I did not grow out of any of these Abnormalities. I became a philosopher (not a Normal vocation for anyone, but especially for a woman). I never gave birth to or raised children. From a young age, I have had asthma and allergies to grass and furry animals. In my youth, in the service of Normality, I would frequently spend an evening at the home of someone with a dog or cat and then spend the night sitting up struggling for breath. Now, I do not even enter a house where furry animals live.

Having lived with ME/CFIDS for so long, I find that it is not always possible to sort out the social Abnormality of my disability from the social Abnormality of my non-disabled characteristics, such as my introversion and my love of contemplation. Introversion is often regarded as a neurotic weakness or a sign of inadequacy, especially in women. The short description I often hear used to praise a woman's personality is "outgoing." The implication is that "ingoing" would be a problem; that problem would be me. Then, too, a love of contemplation is frequently misinterpreted as self-absorption, which is one of the clearest violations of female gender expectations in my society and many others. In fact, contemplative people do not necessarily spend much time contemplating ourselves or anything related to ourselves, but we do want lots of time alone to focus our minds on our own thoughts. Our desire for solitude makes us less available than extroverted people to meet other people's needs/demands, and that is another violation of

female gender expectations. Incidentally, I do not think that feminism has shed or even opposed these expectations of women; although feminist ideals do not require women to be available to meet men's needs/demands, they do require women to be available to meet other women's needs/demands.

Since my illness forces me to rest more than healthy people my age and often makes social interaction, especially with more than one other person, difficult and tiring (and this happens even to people with ME/CFIDS who are extroverts when they are feeling well), it can be impossible to tell whether I dread a party or a meeting because of my personal psychology or because of my illness. It's often hard to tell whether I am shirking my duties as a Normal Woman, failing in my duties as a Good Feminist, allowing myself to be the introverted, contemplative creature that I was born to be, or accommodating my needs as a woman with a chronic illness. More and more, my illness and the enduring characteristics that predate my illness merge into a single concept of myself. That concept changes with variations in the state of my body and mind and situations in my world, as do most people's, but it might be more variable from week to week than the self-concept of a healthy person, and it rarely resembles a person I feel I ought to be.

## ON BEING A FEMINIST PHILOSOPHER WITH A CHRONIC ILLNESS

Since 1971, when I first started calling myself a feminist, I have often had the suspicion that I was about to be kicked out of feminism (or that I had already been kicked out and had not been told). This is partly because I have never come close to fitting my mental picture of the Good Feminist. For one thing, feminism seemed to define itself as an extroverted activity. Could I be a feminist when I spent several hours a day alone, thinking and writing about theories? To make matters worse, I have always been interested in struggles over consciousness, whereas feminist activists and theorists, especially in Canada, tended to favour a materialist analysis of women's lives. Then, when I became ill with ME/CFIDS in 1985, my doubts about belonging to feminism reached a crisis. Much of feminist practice and theory assumed a body that is not sick or tired or in pain and a mind that never gets too exhausted to function. Could I be a feminist when I spent a lot of time resting in bed or lying around on the couch?

In my generation (I am 60), feminism seemed to be for women who loved meetings, parties, phone calls, and marches in the streets—in other words, extroverts whose well-being and creativity did not require frequent periods of quiet solitude. The Good Feminist of my imagination, like the public feminists of my generation, handles work, family responsibilities, and politics with an ease that makes her a shining example, and then "networks" (Remember that word? It still makes me feel inadequate) in her spare time, usually over potluck dinners. Philosophy, on the other hand, required many hours spent alone thinking, reading, and writing, which suited me well. Yet I could not have become a philosopher without feminism. When I was working on my PhD, and for many years after I completed it, most philosophers, as well as the general public, assumed that any serious philosopher was male. (Philosophers usually acted as though this were self-evident while denying that they believed it.) Female philosophers had been virtually erased from the history of philosophy long before I began studying it. Moreover, the philosophical community, with few exceptions, was suspicious or dismissive of anyone philosophizing about women. Feminism gave me strength, guidance, inspiration, and the companionship of other feminists, including feminist philosophers.

Ironically, I have often felt that I was expected to apologize to other feminists for being a philosopher. In the 1970s, when I was working on my dissertation, feminist activists sometimes dismissed or criticized me at meetings or in private for spending too much time on a "male-dominated" and/or "elitist" activity (and yes, academic philosophy was, and still is, both these things). Even now, feminists often speak and write as though thinking, writing, and teaching about oppression and injustice, especially in a university, is not real feminist activity—not like going to community meetings and marching in demonstrations. Of course, one could redeem one's life as a theorist by doing the other things as well, but I never had enough energy to do both effectively, and after 1985, when I became ill with ME/CFIDS, I was lucky to have enough energy to do one effectively.

To create further conflict, what interests me most as a feminist philosopher is consciousness, and the materialist influence in Canadian feminism is quite strong. People who are interested in consciousness are often but falsely assumed to be more conservative politically than people who have a materialist analysis. But an analysis that takes no interest in people's inner lives seems to me inadequate both politically

and ethically since it cannot speak of the suffering of the oppressed as something that is experienced, and therefore it gives us no grounds for objecting to one political situation over another, or, for that matter, to one individual action over another. Although most feminists would deny that they subscribe to materialism if it were put to them in this way, there has been a reluctance to talk about social injustice and consciousness together, a legacy of the power that Marxist analysis exerted in the feminist politics of my generation. Yet I believe that feminism is, in part, a struggle over consciousness—over who pays attention to whom and to what, over who is allowed and trained to think about what, over whose experience matters, how much, and to whom. When people are systematically disadvantaged in a society, their thoughts, feelings, intuitions, and perceptions are systematically ignored or undervalued, and they themselves are taught and continually pressured to undervalue them in relation to those of more privileged people.

Therefore, when I found myself living with an illness that was not going away and began working on my own feminist theory of disability, I wanted my writing about it to include descriptions of my inner life with ME/CFIDS. More intimately than with any other topic I had worked on, my theorizing about disability arose from and affected my experience of it, and I wanted to express this relationship as transparently as possible. It also seemed to me that for women to write about our inner lives with chronic illnesses was a feminist challenge to the assumption that the contents of a woman's consciousness, and certainly of a disabled woman's consciousness, are not worth knowing. However, to begin writing honestly about living with a chronic illness, I had to confront and resist another feminist expectation, one that is virtually unquestioned among academic feminists: that we will wear the mask of success, strength, and enthusiasm and never let it slip to reveal failure, weakness, or doubt. Somewhere along the way, it had become disloyal to feminism to let the mask slip, and by writing about my helplessness to control my body and mind, I was preparing to take the mask off permanently. (I discovered that it is never off permanently, but that is another story.)

Of course, non-feminist social/political groups have expectations of women that are at least equally unfriendly to a disabling chronic illness and an introverted way of life. Feminist expectations affect me more deeply because of the importance feminism has had for me, yet I admit that my concerns about being unacceptable as a feminist are mostly going on in my own head. What does it matter whether anyone considers me a feminist, a bad feminist, barely a feminist, or too selfish to be a feminist? I suppose it matters to me partly because I have always wanted to belong somewhere, yet I learned early in life that I would not feel that I belonged if I concealed important aspects of myself in order to be accepted. And I suspect that there are other women who want to think of themselves as feminists, but have trouble reconciling their feminism with a chronic illness, with a personality that does not fit any feminist ideal, or with the weaknesses, failures, and self-doubt that most people experience. So I ask: Who is feminism for? Is it only for the strong and confident, or is it also for the weak, for the sick, and for others whose bodies and minds are unacceptably different from social ideals?

Because I also identify myself as a person with a disability, I have asked the same questions of disability politics, where the public heroes almost always appear to be strong, healthy, extroverted people who can live as independently as a non-disabled adult. For an insightful discussion of the shame of dependency in disability politics, see Irvin (2004). She is the only disabled person I've come across who praises living in bed: "... I stayed in bed a lot, for I had learned that some people can be more productive, more functional, in bed" (p. 10). The politics of disability rights, public accommodation, and disability pride do not translate smoothly to the problems of people living with chronic illnesses. See Wendell (2001) for more on this topic. Moreover, there is pressure in disability politics, as there is in feminist politics, not to appear to be suffering from anything but social injustice.

## ON THE VALUE OF SUFFERING

When I pay positive attention to other people's differences from Normality, instead of defending my own pathetic share of it, I become aware of how we avoid knowing each other's experiences of suffering. People who are suffering are acknowledged in public or social life only if they can "pass" as not suffering too much and do not talk about it. This prevents those who are suffering (from, for example, physical pain or depression, anxiety, grief, or loneliness) from being authentic in public/social life, and it tends to increase everyone's belief that deviation from the conventional expectations of cheerful confidence and enthusiasm is unacceptable. It also keeps us collectively ignorant of the value of

suffering. There is overwhelming evidence that suffering has value in many people's lives, yet nearly everywhere we encounter avoidance of contact with suffering.

I learned how to live with ME/CFIDS from people with chronic illnesses and other disabilities. Although they make it clear that they are not suffering all the time, I discovered that many people value the suffering they have been through, both for what it taught them and for other ways it changed them. They speak of being forced to develop unknown or neglected aspects of themselves, of gaining new insight, understanding, compassion toward other people who are suffering in the same or different ways, increased intensity of experience, inspiration, appreciation of the present moment, acceptance of things that cannot be changed, and the capacity to enjoy life more. I believe them, and I do not think that they are wrong to value their suffering. On the other hand, I don't think that we should seek suffering or stop all efforts to prevent or cure or reduce it. For one thing, the suffering of illness or disability is different in some ways from the voluntary suffering (such as comes with intense physical training, for example) that people undertake to achieve some goal and with the expectation that it has a time limit. Disabilities and long-term illnesses are often extremely unpredictable in the kinds, degrees, and timing of the suffering they impose on us. And it seems that, at least sometimes, the involuntariness of our suffering in illness and disability, the need to surrender to its demands despite our deeply entrenched habits and to accept radical changes in our ways of living and thinking, is essential to the value we find in it.

It is unlikely that I would have examined my assumption that I was a Normal Woman or my desire to be a Good Feminist without being too ill to pretend to be either, or that I would have experienced the changes in perspective and the intensities of consciousness that come when illness forces me to cancel my plans and retreat to my bed. Kat Duff (1993) describes how living with ME/CFIDS demanded that she make fundamental changes:

> I have always had the tendency to be self-critical, but my illness exacerbated it to the point of self-destruction. So I whittled my expectations down to the mean proportions of my circumstances and told myself: "The way I am right now—today—has got to be good enough," no matter how frightened, silly, stupid, or boring I am. In this move towards acceptance, this cultivated generosity of spirit, I found a modicum of peace, a tolerable way to live while sick. This is one of the ways that ordeals like illness work to destroy our bad habits, grinding us down to an open emptiness. (pp. 96–97)

For several years, I have been working on a philosophical inquiry into the value of suffering and its implications for the ethics and politics of illness and disability. It seems to me that publicly expressed attitudes and policies toward illness and disability, as well as the assumptions of medical ethicists and most other moral philosophers, imply a simplistic picture of suffering as an unquestionable, invariable evil to be prevented, avoided, or ended. This picture conflicts with the value that many people place on their own suffering. Moreover, everywhere there are people whose suffering persists despite all efforts, and I do not see how we can accept and appreciate people who are suffering without attending to and valuing their experiences and absorbing what they have learned from their suffering into our culture. Disability activists worry that when a society abhors the disability, it may be unable to appreciate the people who have that disability and the different ways of being human that flow from it (Asch 2000; Saxton 2000). They ask: Can a society that makes every effort to prevent Down syndrome appreciate people with Down syndrome? (Wong 2002). I am asking: Can a society that is ideologically (if not economically) committed to preventing, avoiding, or ending most forms of involuntary suffering appreciate people who are suffering? Does the goal of preventing unnecessary suffering conflict with helping people to live well with necessary or unpreventable suffering? Can we value suffering without abandoning the effort to prevent or relieve it?